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ABSTRACT

This paper reviews research and evaluates information gathered on disabilities and service development in South Asia, especially India and Pakistan. The concept of "community-based rehabilitation" (CBR), which stresses the need for rehabilitation efforts rooted in the context of local cultural concepts, is discussed. The paper emphasizes the necessity of integrating philosophical and anthropological perspectives into disability information development and community-based rehabilitation programs. The paper recommends rehabilitation efforts that incorporate indigenous disability-related practices, such as casual educational integration, and that integrate local concepts of the child, personhood, ability, disability, and relationships. A review of South Asian information resources, especially those concerning mental retardation, suggests the difficulty of developing indigenous knowledge production when Western material is easily accessible. The historical development of some Asian and European community responses to disability is outlined as background for a description of the rise of CBR programs in India and Pakistan during the 1980s. Among issues discussed are CBR training, information technology, program evaluation, and the roles of foreign rehabilitation professionals and aid and development organizations. (Contains 247 references.) (DB)

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COMMUNITY BASED REHABILITATION:

INFORMATION ACCUMULATION & EXCHANGE.

South Asian Research Notes.

M. Miles

Abstract

This monograph reviews the cultural background to the development of child-focussed disability information in South Asia during the past two centuries, culminating in attempts to introduce so-called 'Community Based Rehabilitation' (CBR). During twelve years' work in Pakistan, developing resources for special needs education and formal and informal rehabilitation services, the author recognised that the 'transfer of knowledge and skills' was inadequate if this information was not rooted in the culture and concepts of the recipients. It must begin with indigenous disability-related practices, such as casual educational integration, and must involve local concepts of the child, personhood, ability, disability and relationships. A review of South Asian information resources, focusing on mental retardation, suggests the problems of indigenous knowledge production in face of the incoming tide of western materials. The need is emphasized for philosophical and anthropological perspectives to be integrated into disability information development, in particular with regard to the concepts of CBR. The historical development of some Asian and European community responses to disability is outlined as a background to the rise of the CBR packages of the 1980s. Research is reviewed on the uses and impact of disability information in service development. Its implications for the transfer of knowledge and skills in CBR development in South Asia are discussed. There are 247 references listed.

November, 1996. Birmingham, UK.

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COMMUNITY BASED REHABILITATION: INFORMATION ACCUMULATION & EXCHANGE.

South Asian Research Notes.

M. Miles

This paper reviews research, accumulation and appraisal of information about disabilities, service development and community based rehabilitation in South Asia during recent decades, and communication studies relevant to disability service development. Cultural and conceptual factors are examined, aiming towards a balance between indigenisation and openness to global experience.

Slow Learners An outline appears elsewhere (Miles, 1993a) of practical experience gained from 1978 to 1990 in North-Western Pakistan, from which the idea of Information Based Rehabilitation arose. That chapter shows much more to be involved than a mere 'transfer of knowledge and skills'.

Through the 1980s, C.Miles and I were learning and discovering the cultural and conceptual background of the people with whom we worked at the many levels noted by Krefting (1993) - the mentally and physically impaired children, their families, teaching staff and physical therapists, trainees from other cities, committee members, local and national government officers in health, education and welfare, and the pediatricians, social workers, psychologists, psychiatrists and educators and researchers in all these fields, with whom we came in contact locally and nationally. We also had opportunities to meet counterparts in other South Asia countries. During that period, our studies were informal and scrappy - picking up what we could, where we could, and reflecting on it while at work.

There were some important things that our Pakistani colleagues told us or tried to tell us in our first few years, which we were unable to hear until we had more experience of Pakistan (C.Miles, 1991). We expected languages and cultures to differ from those of Britain, and that our ideas must undergo cultural adaptation; but it took seven or eight years really to understand that, at a more basic level, concepts of the child, childhood, learning and disability were substantially different from those we knew and which we imagined were universal (Miles & Miles, 1993).

Much later, we realised that those different concepts had some equivalents in parts of British society, modern or historical, of which we knew little. Even now we are unsure of all the implications of these conceptual differences, for the development of special education and rehabilitation in Pakistan - but it is hard to believe that methods and approaches assuming one set of basic concepts of disability, learning and childhood, can

transfer successfully to a society having substantially different basic concepts. Our colleagues and trainees did a good job of mentally juggling methods and techniques between their own concepts and those underlying our suggestions - but at the end, there remains some distance to travel before they reach methods that really fit Pakistani cultures.

Casually ignored Other matters our colleagues did not try to tell us, because they did not think them significant. For example, during our study of casual integration of disabled children in ordinary schools, I reported to my local committee that practically 2% of the children enrolled in school had some disability, at a level noticed by a teacher amongst the 50 or 60 pupils in each classroom - which suggested that at least 200,000 noticeably disabled children were casually integrated across the country, without any attention being paid to them, as compared with maybe 3,000 then enrolled in special schools (Miles, 1985a). Pakistani colleagues were not impressed. They agreed politely that, yes, those children were there in ordinary schools. Such children had been there when they themselves were at school. It was not a big discovery. It was however a confusing discovery, because Pakistan had an influx of foreign advisors, most of whom thought that formal integration of disabled children in ordinary schools should be tried.

This example introduced us to the gulf between official facts and classroom reality, and the contribution of researchers to sustaining the illusion. That 200,000 noticeably disabled pupils might already be casually integrated - of whom the foreign advisors knew nothing - was not 'official' since those pupils were enrolled in school not as 'disabled children', but merely as children. So it could not officially be taken notice of, even though Pakistani educators knew from personal experience that, unofficially, it was a fact. Chatterjee (1951) also reported this from North India. The same phenomenon appeared as a 'research fact' in a Sri Lankan CBR study (Prevention, 1987), but was denied as an 'official fact'. On p.25 of the study, "20.50% of school children, out of a total number of 10,105, in 34 schools are disabled". Yet on p.20, "Disabled children regardless of potential, are kept out of school, and are deprived of a normal developmental process, being over-protected or neglected" - a wonderful triumph of political correctness over mere research findings.

Panda & Goel (1987) lengthily discuss mainstreaming of children with mild mental retardation in India, without mentioning that several million such children are already casually integrated. One Indian report reckoned that nearly 5% of schoolchildren could be considered mentally retarded (Policies, 1975). Paranjpe (1994) remarkably envisages 3% of primary school children having *severe* learning difficulties, but Kuppuswamy (1968) found only 1.4% with IQs between 33 and 69 in middle schools of Mysore. Lall (1944) found 1.6% of *high school* pupils in Agra and Oudh had IQs below 70, an impressive piece of casual integration, totally ignored by subsequent advocates of mainstreaming.

How do such children fare? Damle (1952/53) reported the misery of families at their retarded child's school failure; but Kamat (1951, p.219) noted that a teacher, with a pupil aged nearly ten who was doing well in the infants class, would not believe that the boy was mentally backward. Ramanujachari (1962, p.73-74) noted that rural teachers "blissfully unaware of the principles, methods and techniques of modern education seldom attribute [pupils'] backwardness in study to defective mental development. Thus poor children become the victims of [teachers'] taunting and all sorts of punishment." Some attitudinal change may have occurred since then; yet Narasimhan and Mukherjee (1986, p.61) commenting on 'automatic integration', saw little benefit as "the teachers in normal schools are not equipped to look after them".

History & Anthropology As for historical and anthropological studies relevant to disability in Pakistan, our colleagues uniformly doubted that anything had been done, or was available.

Such doubts were largely but not entirely justified. Pakistan's libraries contain little pertinent historical or anthropological material; of the material that is potentially interesting, e.g. the educational and psychological studies of children reviewed in Pervez (1989), the bulk are unpublished theses by novices. Doctoral studies on education and disability in Pakistan, carried out by Pakistanis in the West, are not automatically copied to Pakistan's universities. In England I read an American thesis on mental handicap in Pakistan by Haider (1971), which would have been useful to the government in the mid-1980s when national policies were being drawn up. It also gave some cultural and anthropological background - which had taken me several years to piece together painfully from other sources. This sort of useful work is done yet is not available when needed. Recently I read more unpublished disability-related doctoral theses at the Indian Council for Social Science Research library, Delhi. Such theses are not widely known and read in India. At least the ICSSR systematically publishes listings of research, and makes material available by mail. Computerisation of its database is beginning.

The history and anthropology of disability has hardly begun as a field of study in South Asia. Even in Western countries with vastly more investment in social and historical research, such studies have barely 20 years' depth. In the past four years I took the opportunity to scratch the surface of Indian disability history, through materials in European languages in England. Even within this limited field of search, there is plenty of detailed disability-related information to be found, certainly back to the 1760s; plus a lot of less specific material from antiquity, in the medical, legal, religious and dramatic literature of ancient India, available in translation.

This introduction indicates some of the interests and limitations of what follows. Along with actually developing services, part of my aim over 16 years has been to facilitate the indigenisation of special education and rehabilitation in Pakistan, by discovering what happened before formal services began, how people managed disability informally with

traditional methods and customs. Actual indigenisation, i.e. the blend of traditional and modern approaches, lies of course with Pakistanis. That process is under way. While still believing that Asians can learn something from Western experiences, I slowly came to see that the process is much more complex than merely a 'transfer of knowledge and skills'.

We have been misled by the example of physical medicine. Many physical techniques and drugs are of universal application; whereas rehabilitation necessarily involves culture and concept, since it involves adjustments in the relationships between disabled individuals, families and communities. In northern Pakistan, there has been about 130 years' exposure to European knowledge and skills in physical medicine, after 2,000 years' accumulation of knowledge, e.g. at the ancient Medical School of Taxila, from Chinese, Aryan, Persian and Greek sources. On these time scales, the acquisition of formal rehabilitation knowledge and skills is very recent.

The fact that basic manuals are available for physical disability and blindness has misled people who specialise in those fields into thinking that there are 'enough' basic CBR manuals - though families and frontline workers continue to be baffled by children with problems of communication, behaviour and mental retardation. The latter problems are much more culture-bound than the former, so are harder to write about both simply, clearly and with sufficient detail to get good results. The problem is not the professionals' wish to control the information, but the sheer difficulty of the exercise.

This paper is practically confined to material published in English, on South Asia and Western Europe - but the existence of important experiences recorded in many other languages is acknowledged. (We should learn more of them). Some types of information-related research completed, under way, or needed, will be sketched with examples and comments on their relevance to the development of rehabilitation services. The relevance is sometimes longer-term, concerning the historical processes of accumulation and transmission of human information - accelerating in some directions, slow and cumbersome in others. An historical base at least provides perspective.

BIBLIOGRAPHICAL STUDIES, ACCESS & INDIGENISATION

The disability literature in English originating in Western countries is vast and accelerating. No database yet tackles the pre-electronic backlog, i.e. from 1970 back some 200 years. (Maybe there are American efforts to do so. With a thesaurus of relevant terms, on-line searches of general union catalogues are feasible). For developing countries, bibliographic and informative efforts on recent disability services are under way between AHRTAG, London, and the Institute of Child Health, Uppsala. Other players, e.g. UN agencies, the International Disability Consortium, ICACBR, Handicap International, Rehabilitation International, are interested. Canadians may have greater exposure to French-, and Americans to Spanish-, language sources from developing countries.

There is little more coordination than in 1985 when I described the situation (Miles, 1985b, pp.45-46), but the amount of information and number of players has greatly increased, numerous directories are available, and many will be accessible on the Internet within two years. Several hundred Internet sources and discussion groups can already be accessed (see Brown, Roth & Duncan, 1995), and major advances are expected. The swing from information shortage to information overload is rapid, but third world information frustration will probably remain constant, as 98% of Internet output is preoccupied with western domestic issues. (A search for 'Community Based Rehabilitation' on the World Wide Web in September 1995 found 80 locations where posted material used this phrase. All but three were North American and little relevant to developing countries).

Western bibliographies are unlikely to make serious use of South Asian disability literature and information, unless interested organisations in these countries take a hand. Westerners generally assume that little has been done, written or published about disability in Asia, and that what exists will be of poor quality. One way to combat this ignorance is to make bibliographies and reviews widely available.

I have some idea of the extent of the English-language disability literature produced within Pakistan (the Urdu material being still of negligible quantity) and Afghanistan; and recently have been estimating the equivalent in India of English-language published books, journal articles and doctoral theses. It seems feasible for the disability literature of every Asian country to be listed, and lightly annotated (to the extent of keywords, where titles are not explicit; and neutral indication of status, e.g. research report, popular overview, self-advocacy manifesto, Government statement etc), at modest cost. Some countries already target full general bibliographical control, from which disability literature can be extracted and supplemented with some of the relevant grey material. For foreigners wishing to know the state of social science information in India generally, a useful overview was edited by Binwal, Chandel and Saraf (1990); though much electronic systems development has since taken place (cf. Heitzman, 1992). Rehman (1990) and Sardar (1988a) provide similar overviews of information development in Pakistan and the

Islamic world, up to the advent of electronic systems. Kerr (1979) on information gathering in Afghanistan in the early 1970s gives a realistic introduction to constraints *in rural areas* of the subcontinent.

At the headquarters of India's District Rehabilitation Centre scheme, a small department aims to keep track of current disability literature, with barely adequate resources and no facility for retrospective work. Set up in 1987, this is called the National Information Centre on Disability and Rehabilitation. The title hardly fits the room at present occupied. Further resources are urgently needed.

There is much to be learnt from the past, but people do not seek lessons if they believe that no records exist. Some impression of the size and feasibility of the exercise could be gained from the example of the disability literature with which I am most familiar, i.e. mental handicap and childhood learning difficulties. Bibliographic reviews have appeared in studies by Das (1968), A.K.Sen (1976), Agrawal (1977), Ishtiaq (1977, pp.42-61, 223-237) and A.Sen (1992, pp.63-113, 270-294) for India; Miles (1991b, pp.52-58, 67-69) and Miles & Miles (1993, pp.215-235) for Pakistan. The references in papers edited by Zaman (1990) give an indication of the state of play in Bangladesh, while Miles (1993a) lists disability literature pertinent to Afghanistan, lightly annotated. Earlier Indian psychological studies (1916-1950) are usefully reviewed by Mitra & Mukhopadhyay (1958; see also Pareek, 1957; Prabhu, 1974). Psychological research in Pakistan is reviewed by Zaidi (1975) and Ansari (1982, 1989). (I have not yet read a very recent bibliography on mental retardation and other disabilities in India by Venkatesan & Vepuri, noted in *ActionAid Disability News* 6 (2) 1995).

Earlier disability studies in India, e.g. by Bhatt (1963) and Taylor & Taylor (1970), give guidance to a range of rehabilitation literature from Independence onward. Neither is reliable for earlier work, for which references in Miles (1994, 1995 & in press) make a start. Recently I compiled bibliographies and historical reviews on microcephaly centred on the shrine of Daulat Shah in the Punjab from 1850s up to date; on goitre and cretinism in South Asia from the 1780s to 1920s, after which standard medical indexes exist. A similar exercise is in hand on lathyrism in South Asia. An extensive bibliography and review on poliomyelitis in India is in press, by Wyatt.

A range of earlier references on deafness and blindness appears in relevant works in Miles (1994). Punani & Rawal (1987) include a recent bibliography on rural blindness. The National Association for the Blind (1978) catalogued 79 surveys and studies, 1944-1977. More focused bibliographies are available with the National Institutes specialising in these disabilities (cf. references in Singh, 1989, 1990). Earlier serials such as J. Rehabilitation in Asia, Social Welfare, Blind Welfare, Mook Dhwani, The Deaf in India, Indian J. Mental Retardation, Indian J. Physical Medicine & Rehabilitation, NASEOH News, and more recently Disabilities & Impairments, ActionAid Disability News, Indian J. Disability & Rehabilitation, SAMADHAN News, and the quarterly newsletters of the

National Institutes, should fill up the picture, together with material from standard journals in psychiatry, paediatrics, orthopedics, ophthalmology, otorhinolaryngology, psychology, social work and education. Some of these have long been scanned by international indexing services. However, complete runs of some serials, such as J. Rehabilitation in Asia and Indian J. Psychology, are available in very few places. Microfilming and distribution is an urgent need, before the earlier parts disappear entirely. Indian institutions have been microfilming medical journals for half a century (Microfilm, 1948); the disability field lags behind.

Access & Indigenous Research Bibliographical control and access are basic to indigenous research, and to the cultural independence of researchers in developing countries. A sad feature of published papers in South Asia, across the social sciences, is the excessive citation of western sources - many being of doubtful relevance - and the neglect of reference to indigenous material.

This must be due partly to the 'colonised mind' syndrome, partly the difficulties of access. Two centuries' worth of disability experience, studies and reports in the Indian subcontinent prior to 1960, are now little known, and not readily accessible. Some of it is easier to find in England than in South Asia. Qureshi (1989), speaking of Pakistan but applicable more widely, complained that "In a country which has no sound traditions of preserving its historical source material, archives and libraries are bound to be grossly understocked and under-utilized." We can change this, and ought to do so, at least in the disability field. The actual quantities of material can feasibly be tackled. In fact, ESCAP was already asked some years ago to assist such an exercise (Report of the Regional, 1987, pp.42-43).

Lack of historical roots and reference, plus the dominance of Western output, contributes to the tentative and make-shift feel of current Asian disability writing, and increases the difficulty of formulating criteria to evaluate the contributions of Western disability researchers... or, as it may be perceived, to stem the flood of cultural neo-colonialism. Debate on 'captive minds', indigenisation, and the dominance and destructive effects of Western (male?) epistemology, are worldwide and transdisciplinary. Ake (1979), writing from a Canadian university but published in Nigeria, asserted that "..the bulk of Western social science on Third World countries amounts to imperialism and is worse than useless" (p.99). That the 'imperialism' may be unconscious (p.102) does nothing to divert Ake's thrust. Ten years earlier, Pieris in Ceylon (1969) had noted that the writings of Asian social scientists "..were invariably addressed to an invisible jury located in some intellectual centre of gravity in the West."

Disability research has been so marginal in developing countries that indigenisation has hardly surfaced yet as an issue. Undoubtedly it will, as hardliners criticise the entire enterprise of Western science and its dominance of worldwide research agendas. Sardar (1988b, pp.1-3) sees modern science as fundamentally violent - i.e. it violates nature, it

dissects and atomises and ultimately destroys the unity of human values and meanings. Though exaggerated, Sardar's point sounds familiar in the disability field, where a child in difficulties may be carved up among ten mutually suspicious specialist departments. The strength of science lies in its self-inflicted violence - every part of modern scientific knowledge is under continuous and vigorous assault and development by scientists - in contrast to knowledge systems that were completed centuries ago and can be learnt but not questioned.

Social science research in India is some years ahead of Pakistan, Nepal or Bangladesh, so the previous remarks may seem remote or even insulting to younger participants. The days have passed when, as Sabzwari remarked in 1963, "In a country like Pakistan, where research is still in its infancy, it is not possible to draw a line of demarcation between the expressions 'scientific research' and 'accumulation of information'" (p.273). Yet recent Pakistani commentators find little evidence of progress. Hoodbhoy (1991) on research in the physical sciences, Ahmed (1990, Foreword viii) on anthropology, Shah (1989) on psychology, and contributors edited by Hashmi (1989), give a dismal picture. Perhaps they are over-pessimistic. The younger generation of social and educational scientists in Pakistan certainly does not lack intelligence, enthusiasm or application. Yet there is hardly any 'research culture' to guide and encourage these assets. There is little funding for research of any sort, and few rewards for the researcher. Library resources are scarce, publication channels are weak, while promotion comes by personal influence, rather than by proven ability in published research. Such obstacles face any young field of research, but may yield slowly before a determined onslaught. Perhaps some western interest might help - if done with a rare degree of sensitivity, lightfootedness, and willingness to get out of the way when no longer needed?

Informing the West also Western ignorance could further be reduced if South Asian writers made their work more accessible in the West. For example, a single copy sent to The British Library or virtually any public or educational library in the UK, becomes accessible to 40 million readers for the next century or two, through inter-library loan. There are also specialist libraries, e.g. those of the Royal National Institutes for the Blind and for the Deaf, having international collections and accessible without formality. There are equivalents in continental Europe and North America. Monthly updated on-line open access national cataloguing with international links, which has developed rapidly in recent years, makes it possible to locate material quickly anywhere in UK.

By the time more non-western anglophone countries have developed their library services, current western methods will have been overtaken by world-wide electronic access, and academic (low or nil profit) publishing will have changed radically. Recently, a Japanese team released the full transliterated text of the Sanskrit Mahabharata on the Internet - a colossal piece of free publishing. Within days it was reposted at several local sites, and was being downloaded by individual Indologists and by Asian Studies departments. Textual work that would have taken a lifetime before computers, can now

be undertaken in hours by anyone with a cheap PC and widely available software. Disability information relevant to South Asia need not wait. We should expect non-commercial material, including *ActionAid Disability News*, to be on the Internet within the next year or so. (This newsletter is about to be relaunched as the *Asia-Pacific Disability Rehabilitation Journal*, with an international editorial board).

PHILOSOPHICAL, CRITICAL & CONCEPTUAL

The most basic research needed for third world service development is the least likely to be done or even considered, i.e. studies across the spectrum of meaning and significance in 'rehabilitation' (cf. Matkin, 1985). Present rehabilitation efforts battle along with a largely unquestioning activist, humanist, 'Rights and opportunities' ethos, tacitly assuming that the Rights are universally agreed and worthy. Yet for the past 30 years such global assumptions have been steadily attacked and eroded - both in detail (e.g. the grand metanarrative is often propounded by people with some personal stake in it, whether conscious or not), and in principle (i.e. the range of human cultures is too great to be swept inside any single wonderful scheme, however passionately its proponents persuade themselves that they believe in it).

Philosophical research is not going to please people seeking 'answers' that will relieve them of the task of daily reflection on their work. Fundamental research seldom makes life easier in the short term; but it may determine what is common practice 30 years later. If such research is not done, or is done dishonestly or reported carelessly, common practice 30 years later will be that much more muddled and ineffectual. We should, however, be clear that neither fundamental research nor CBR will 'make people happier', nor make them more alive, than they are now. Perceptions will adjust to keep pace, so that people will feel just as happy or miserable as they ever did. Some will *do* more activities; but they will not *be* any more alive.

Religions A glance through the disability track record of major eastern philosophies and religions, including Judaism and Christianity, suggests that there are major differences between their main historical thrust and the philosophical underpinnings of, for example, the World Programme of Action Concerning Disabled Persons (1983). A recent study (Miles, 1995), listed items from the historical treatment of disability in Hinduism, Buddhism and Islam that would be viewed as positive by 'right-thinking westerners', as well as elements that would seem negative to many westerners and some easterners. That study is at an introductory level, partly because there is very little previous literature. Bhatt (1963) and Sharma (1976) have a few notes. Glucklich (1984) reviews disability in Dharmasastra. Younghak (1985), Ninomiya (1986) and Wertlieb (1988) have written on disability in Japanese, Korean and Judaic thought, providing some perspective. Bowker (1970) examines suffering in world religions.

The research literature is negligible, though it is hardly disputed that religious beliefs are a major factor shaping thoughts and attitudes among the bulk of the South Asian population. Yet in the CBR literature one soon finds dismissive comments about the attitudes of target populations towards disabled people, which are said to be based on 'false' beliefs, e.g. that disability is a punishment for one's sins either in the present or past life. It is then suggested that 'mistaken beliefs' should be replaced by the facts... which turn out to be modern 'correct beliefs'. Even an official report of the World Bank cannot conceal the disdain of its author towards the attitudes of Pakistanis to disabled

people, said to be "tainted by cultural superstition" (Lynch, 1994, p.12). One might ask whether Reagan's presidency of the USA was 'tainted' by his wife's use of astrologers at the White House, and whether that was a 'cultural superstition'.

That disabilities are punishments from unseen forces such as ancestors to whose spirits one has been disrespectful, is not my personal belief; yet it seems a little arrogant to dismiss religious and traditional beliefs without making some effort to understand what is believed, how it fits into the believers' general world view, whether beliefs are undergoing changes, and how far they might be held concurrently with some of the belief-pictures of modern medical science.

The defective gene theory of certain disabilities remains largely a belief in unseen forces unless one credits the interpretation placed on patterns of dots seen under a microscope by people in white coats. The white-coat theory, in which ancestors send harmful material randomly to a statistically calculable proportion of their descendants, is obvious nonsense judged by the belief systems of much of humanity. In such systems, the 'reason' offered by the white-coats looks like 'fatalism', i.e. lacks any reasonable explanation of cause and effect that could be linked to one's conduct in present or past life; whereas, to the white-coats, it is the 'primitive' belief systems which appear 'fatalistic' (cf. Coster, 1934, pp.86-88). There is room for much more study of the effects of such conflicting causation beliefs, on people's management of their own and others' disability. Further, the religions teach a measure of dispassion towards suffering or disability, as having little ultimate significance. In some religious world-view - which have meaning for 3 to 4 billion people - one may welcome some dependency and disfigurement, to counter the tendency to illusions of youth, beauty and independence. The construction of life-goals from consumer advertisements, rather than from any more formal religion, is still a minority, urban disease.

Sociology Rears its Ugly Head... When half the field-labourers of an Indian village are crippled by lathyrism, is it more reasonable to attribute the calamity to the motiveless and apparently random action of an unseen neurotoxin; or to the victims' foolish consumption of *kesari dal* (which, according to Kislev, 1989, has been cultivated for the past 8,000 years)? Major Acton, professor of pathology and bacteriology at Calcutta, whom one might have expected to be hard-boiled and to have little time for sociology or wishy-washy welfarism, believed 70 years ago that, since the villagers were not naturally stupid and they would live on an exclusive diet of *kesari dal* only when compelled by famine to do so, "The solution is therefore a sociological one, and should consist... in the abolition of the harwar [bonded labour] system, the controlling of food prices and relief during famine years..." (Acton, 1922).

In the 1990s, some of David Werner's young CBR colleagues have risked their lives for their belief that disability in Mexico's Sierra Madre arises from gross socio-economic inequities, of the sort earlier criticised by Acton. Does CBR demand of its proponents

that they be ready to die for their beliefs, in armed class struggle? The UN agencies have hardly emphasized such a notion, in their sales pitch to governments; but it highlights the need for basic studies of the belief systems underlying various approaches to disability prevention and service development.

The philosophical/conceptual problems mentioned in my introduction were not, of course, fresh discoveries. We were merely ignorant of the relevant literature, an ignorance perhaps shared with others working in service development. Many of the philosophy and sociology papers I come across are badly written and deeply boring; a few, however, leave me confused but excited, a feeling that persists through several re-readings. Two of the latter with relevance to third world disability service development, are by Shweder & Bourne (1982) and Dossa (1989). Both discuss cultural and conceptual differences in ideas of personhood and human relationship; the former, in particular, reports a study eliciting differences in concepts of the person between Indians and Americans. They reinforce my dismay on seeing the steamroller of western rehabilitation ideologies crashing through the urban streets and gardens of South Asia, heading out towards the villages, bearing the `CBR' banner, supported by the conventional rhetoric of normalisation, equalisation, independent living and so forth.

Think Local, Act Global? The British traders, missionaries and colonial administrators, from about 1800 when they settled down to the idea that they `controlled' large chunks of India, did so at least partly in the belief that they were benefitting the population, and partly in the belief that they were being careful not to trample on indigenous customs and beliefs. They might have been partly right in their belief, for part of the time; but it is now easier to see damage which they caused without ever being aware of it, by imposing philosophical and conceptual assumptions that were too basic for them even to realise they were doing so. Many social reforms in India during the 19th century might have happened anyway in due course, through the agency of indigenous reformers, after lengthy internal battles. That they happened with some external engineering meant that they could not be the result of a natural, incremental evolution of public opinion. British administrators were not merely technical advisors, facilitating, or sometimes retarding, change already desired and directed by indigenous leaders. One could argue that western disability advisors in the 1990s are comparatively powerless; but on the contrary, I believe the steamroller is now more powerful, equipped with a panoply of modern information technology, nailing each incontrovertible `fact' into place with a dozen remote research studies (carried out on that universal, omni-cultural subject, the American College Student?) and with its retinue of servants mass-programmed and intoxicated with the rhetoric of their ideological discourse.

Take, for example, deinstitutionalisation and normalisation, "..probably the most controversial and emotionally charged issues in the field of mental retardation" (Landesman and Butterfield, 1987). These western movements or issues, along with `integration' and `independent living', involve assumptions about concepts of personhood,

individuality, relationships, families, the meanings and goals of life, the ethics of making choices for other people etc, that are debatable within their native context. Yet the slogans, the journal articles, and the western textbooks which have passed their sell-by date and are dumped in third-world bookshops, reached Pakistan during the 1980s without exposing the conceptual assumptions or disclosing the ongoing controversies from their places of origin. Such problems are indeed discussed in a few books and journals (e.g. Rose-Ackerman, 1982; Baldwin, 1985; Barton, 1989; Cole, 1989; Hayes, 1985; Mostert, 1991; Chappell, 1992; Wedell, 1995) - which have low or nil circulation in South Asia. Eedle, in 1972, discussing various sorts of educational integration around the world (pp.100-102), already noted warnings against "excessive enthusiasm" for these experiments. I am not taking sides on any of these issues; but pointing out that most of the camel is invisible when it first puts its head in at the door of the tent. There is more to follow.

Eugenic Rules, OK? There seems to be virtually no engagement between these modern western camels and the South Asian writers such as Quddus (1990), who approvingly quotes American sources on mental handicap from 1900-1930s, classifies mental retardation in terms of "morons, imbeciles and idiots", and asks of the latter, "Would it not be better quietly to put them out of their misery?" There is no apparent engagement with the still-current Indian sociology textbook (Mamoria, 1981), endorsed by a former director of the Tata Institute, which suggests for the "feeble-minded" and "subnormals", that "Selective sterilisation of defective types would not only decrease the present costs of these unfortunates to the society but also diminish the economic handicaps of the social normals. Maintenance of the purity of racial stock has a special appeal to the Indian sentiment. Hence, all suitable measures that provide for it by education or legislation should be welcomed." (p.441) Fifty years earlier, Pillai (1931, pp.108-113, 163) proposed an identical solution for "moral imbeciles, idiots and similar other diseased or tainted persons" in rural India, endorsed by two senior British doctors - but that was before the Nazis' sterilisation or murder of disabled people demonstrated the ethical problems along this path.

Neither Quddus nor Mamoria necessarily represents current educated opinion in the subcontinent; but it is odd to find such sharp discontinuity between material openly published in supposedly serious books, and the rhetoric of CBR in the same region. On another continent, the pragmatic answer of poor Brazilian mothers may be to "let go" (neglect to death) their disabled babies, who are believed to be 'unprepared for the struggle of life'. Scheper-Hughes (1992, pp.353-393), who lived among these women, describes rather clearly the logic of the situation, though it offended her own concepts of justice and intervention. It would probably offend CBR advocates even more - but they seldom raise their babies in shanty towns.

If You Can't Think Global, At Least Think Conceptual differences in rehabilitation approaches are addressed vigorously by Frans Vreede and his Study Group on

Transcultural Rehabilitation Medicine (1993). Forty years earlier Vreede published an introduction to Hindu philosophy, and in the meantime worked in Indonesia and taught rehabilitation medicine in the Netherlands, which accounts for his distinctive points of view and unusual methods of communication. His recent book distils Vreede's lifetime of rehabilitation practice and reflection, seeking to delineate the essentials, which can be applied in local situations. It is a philosophical counterpart to the well-known grassroots manuals by Werner and by Helander et al; but demands much more thought on the reader's part. Associates are preparing an annotated bibliography of relevant materials, particularly in physical disabilities (A.Vreede, 1994).

Serious practical study of conceptual differences in disability service development has not, however, been reported yet in the subcontinent, to my knowledge. Such issues are raised by C.Miles (1993) in her study of educational language and culture in Pakistani children with mental handicap, in both Pakistan and UK, and also in Miles & Miles (1993). Leotard (1993) in Baluchistan, and Jaffer (1993) in the Punjab, both identify failures of CBR programmes through a lack of attention to the cultural specifics, and to "...pre-packaged, standardised programmes which involved no analysis of local conditions prior to project design and no involvement of the community in planning."

Project, programme and evaluation reports in *ActionAid Disability News* in recent years suggest, however, that disability development is proceeding with a wide variety of approaches, with some creative reinterpretation of imported ideas. This may be one of the happier results of the fact that most South Asians involved in grassroots disability work think about what they are doing in several hundred languages other than English. While assimilating ideas to their mother tongue, and trying to make sense of them, some conceptual leaps are likely. This linguistic phenomenon seems even more likely in disability service development in China, where English-constructed thinking is rare but the use of indigenous rehabilitation techniques such as Qi-Gong (Lee, 1983) and "acupuncture, traditional massage, manipulation and Chinese herbal drugs" (Tizun, 1994; Zhuo, 1986, 1988) have strong standing, and there are strong existing patterns of in-family care for disabled people (Dixon, 1981). The important thing is that what people engage in should make sense to them, in their own terms.

Colitically Porrect No corner of South Asia lacks at least some highly evolved culture, in which at least some high notions of caring and mutual responsibility have a place (often alongside ferocious exploitation). The caring side can and should be appealed to - but the shape or form in which communal response is made, in terms of enabling disabled people to benefit from new knowledge and skills and value, is both hard to predict and "seldom complies with Western beliefs and attitudes about the value of human life" (Wolffers and Finkenflugel, 1993), let alone complying with the more rigorous standards of western CBR advocates. In fact, Groce & Zola (1993) note that the stereotypical western beliefs and ideals are not so common even in "white middle-class America of the 1990s"...

The conflict of approaches is noted by Kugelmass and Setiono (1991). Kugelmass studied and reported on childhood disability and caring in Indonesia - only later becoming aware of her Indonesian collaborator's feeling that "the conclusions of the research did not take other realities that exist in her country into account." The American, far from taking a critical stance, emphasized the "patience and warmth that characterizes the interactions between parents and children." The Indonesian, viewing her own society without fear of appearing culturally arrogant, thought that the virtues praised by her foreign colleague were not always positive if they became overprotection or a fatalistic acceptance. The American Werner (1993), having learnt the cultures of the Mexican Sierra Madre over 25 years as an expatriate visitor, could point out the same problem as Setiono does in Indonesia, without embarrassment. The strong in-family care approvingly mentioned by Dixon in China (1981) appears distinctly less rosy to Pearson and Chan of Hong Kong, who actually interviewed mothers with handicapped children (1993).

There is, in fact, no guarantee that the caring response will be forthcoming. Jobert (1985), in a detailed review of an earlier populist grand scheme for community health volunteers, which proved to be deeply flawed, noted that "The broad transformation expected was to appeal only to the spirit of social service that is found in each community..." ...despite the objection raise by some that the idea of 'community' in the Indian village is mythical and that social reality consists of a series of self-perpetuating oligarchies, progressively more exploitative at each lower level.

How far this objection is thought valid is partly a matter of political beliefs; but at least one UN disability document found that "Many surveys and other research studies on all regions of the third world agree that deep and pervasive social, economic and political divisions mark the rural communities in which the majority often live a marginalized existence." (Disability: Situation, 1986, p.40). Such thoughts betray a deep scepticism about CBR among UN staff - it is significant that the Standard Rules (1994), adopted by the UN General Assembly for the global uplift of disabled people, studiously avoid using the term CBR. Scepticism is normally concealed in publications, but Momm & König (1989) had the courage to break out and discuss the limitations of community care, whether reported from the USA (p.2) or in the ILO's accumulated Third World experience.

Even if one believes that a margin of magnanimity should be discernible in whatever South Asian community, it may shrink or vanish in times of severe economic pressure. This became clear after an analysis of CBR projects by Ganguly & Brar (1993): "..the overriding conclusion of these projects is that where the primary focus of the family is on survival and overcoming poverty, involving the energy of both parents [,] commitment to the home management of disability is minimal." A similar finding was noted by the WHO, in a massive global review of more than 850 documents ("16,500 printed pages in English, French and Spanish") on Primary Health Care (Review of Primary, 1982, p.105), i.e. that "..community involvement in PHC never begins effectively in reality

prior to communities reaching a certain threshold in economic, social, and educational development."

Yet WHO-CBR, even in the more modest version as conceived around 1982, clearly required an even higher threshold. The criteria for selecting project areas for field-testing CBR were (a) interest and cooperation by national and local authorities; (b) a resource centre (rehabilitation institution, medical college) willing to collaborate for training, referrals etc; (c) an operating primary health care scheme and related infrastructure; (Community Based, 1982, p.9). The earlier rhetoric of CBR tended to denounce or denigrate rehabilitation institutions, even though field-testing of WHO-CBR depended on institutional support. Thus Helander (1989) claimed that "When CBR is applied with good management, it will lead to results that are as good as, or better than, the results obtained by professionals working in institutions." So what did the institutions have to offer CBR? In fact, this sort of exaggerated claim depended on defining "socialization... as the main objective of rehabilitation" (ibid.), and excluding most of the severely disabled people who are referred to professional expertise from the local community level.

Carpentier (1994) comments that "With one exception, the CBR services in some 20 developing countries have all been established only after the identification of an existing special school or centre which could serve as a base and resource centre for the CBR programme. When no such institution existed, the CBR programme was established only following the opening of a new school or centre. The one exception is in Gaza, where there are serious problems in running CBR because there is no resource centre and therefore no nucleus of professionals." An evaluation report on the Guyana CBR programme (J.Miles & Pierre, 1994) found that a resource centre "may actually be indispensable for the full realization of programme objectives" (p.25).

African Differences Cultural and conceptual differences in rural Africa might not actually be any greater than those of traditional Asia, when compared with Western views, but are perhaps more sharply delineated. Cusson, working with rural disabled Cameroonians from 1970, slowly and painfully learnt to hear what they were telling her (1976). Walker (1986) surveys disability attitudes studies from a range of African countries, and notes their variety and the considerable number of positive and supportive approaches. Jackson & Mupedziswa (1988), Burck (1989), and Kniel (1993) depict some of the significance of disability in Zimbabwe. Kisanji (1995) does so for Tanzania. Further studies in Botswana, Kenya, Somalia, Uganda and Zaire appear among an excellent new collection edited by Ingstad & Whyte (1995).

Without having reviewed the extensive literature cited in these studies, so far as I know Burck's is the only detailed, published, English-language study in the anthropology of disability that took place specifically in the context of a CBR programme. It is undoubtedly a model, in both meanings of the word, i.e. it is done very competently, and many more such studies are needed. Ironically, it is at present out of print. Burck

remarks (p.4) that "Recent criticism on community or primary health care to the effect that most community-oriented health services do not sufficiently take the ideas and practices of the community into consideration, but are, instead, based on scientific medical ideas that contradict the ideas held by the rural population, is equally applicable to community-based rehabilitation."

Serpell, Mariga & Harvey's overview of mental retardation in Africa (1993) makes similar points about the conceptualisation of the child, of intellectual development and of education. Though little of this has penetrated into international debate, they believe that "...the system of constructs and practices encoded in these African cultures constitutes a coherent alternative to those represented by the system of formal schooling adapted from exogenous Western, Christian, or Islamic traditions." Several recent papers by Kisanji underline this point.

The Academic Mills Grind Slow. Recognition of cultural and conceptual alternatives, and their implications for the sharing of rehabilitation information, has been slow. Papers on disability and culture by Hanks & Hanks (1948) and Edgerton (1970, 1984) were early landmarks; but until cross-cultural studies of medicine, education and psychology were better established, the anthropology and sociology of disability in non-western societies had to wait. Earlier work in anthropology and cross-cultural studies in mental health is well documented by Favazza & Oman (1977). Studies of European disability history grew during the 1980s (see references in Woodill & Hanes, in press). Groce (1985, 1986) bridged across history and anthropology in her ethnographies of deafness and mental retardation in 19th century small town America. Efforts to put a framework round the complexity of culture and disability have followed (e.g. Scheer & Groce, 1988; Gartner et al, 1991, pp.17-56; Peters, 1993; Mallory et al, 1993; Culture & Disability, 1993; Ingstad & Whyte, 1995), but there is a long way to go.

A bibliography of "Aspects Socio-Culturels des Handicaps" (Paichler et al., 1987) annotated in French but giving mainly English citations, suggests that French-language work in the field has not advanced much faster. Neubert & Cloerkes's bibliography (1987) gives both German and English works pertinent to the field. The serial *Zeitschrift Behinderung und Dritte Welt* (ISSN 1430-5895, formerly 0944-1417) published since 1990, documents increasing interest in German universities and agencies. (Psychology, where important cross-cultural work and progress has been made since the 1960s, is not discussed here, since it is the province of other speakers of much greater experience, at the Bangalore symposium).

Is CBR Falsifiable? This paper was begun the day Karl Popper died (17 Sept. 1994), so the `philosophy' section must glance at the question whether CBR is falsifiable - whether there is in CBR any testable hypothesis for which evidence could be gathered that would either prove or disprove it. Without some such hypothesis, having potential for methodical testing, CBR is purely an ideology or belief system.

In CBR writing of the 1980s, there was much denunciation of wrong ways and declaration of the True Path - but without supporting evidence. One had to make a leap of faith, and walk on the water. Some people got soaked. Perhaps CBR has merit as a belief system; but one cannot do scientific research on beliefs. If the system is constructed so as to exclude the possibility of any evidence that could disprove its creed, then we cannot do scientific research on it.

Only two aspects of this complex question will be examined. One is the question of definitions. Many activities have adopted the 'CBR' slogan. Some are seen by their participants as 'successful', others as 'unsuccessful'. A similar range of verdicts is beginning to be heard from external evaluators. CBR advocates are tempted to claim that where there is 'success', the activities were genuine 'CBR'; but activities judged to have failed, were never 'true CBR' - either not being set up in the correct way, or not implemented with the true spirit, or unfairly damaged by external factors, or being judged by inappropriate criteria, or some other let-out.

Vendors of snake oil have a similar range of escape clauses to appease dissatisfied clients who have paid their money and used the oil, but not been cured of baldness, impotence or whatever. It would be sad to have to classify CBR along with snake oil, for lack of clear definitions. A recent world conference report emphasized the need to view CBR soberly. "CBR is not a panacea, nor does it provide a universal template for the future. On the contrary, unrealistic and sentimental reliance on CBR can do a disservice to its aims by discounting the serious social and economic obstacles to successful implementation." (Final Report, 1995, p.45).

Dr Helander rightly notes in various places that much of what has been evaluated as 'CBR' was not CBR by his criteria. However, definitions of CBR that involve terms like 'commitment', 'strong political motivation', or 'equitable distribution of resources', tend to exclude it from the realm of the falsifiable, since these imponderables can hardly be controlled or tested experimentally. In fact CBR, by anyone's definition, is nowhere a *completed model* that can be examined. Helander (1993, p.189) modestly admits that "Several decades of work will be needed to identify the appropriate ways of arriving at a system capable to deliver essential services to all those in need."

The second aspect is that to ask whether we could do scientific research on CBR, after the above thoughts on conceptual differences, begs the question, who are "we"? If CBR can 'really be understood' only by Disabled People, or Black People, or Third World People, or Members of Oppressed Minorities, then CBR is a belief system. Even if the excesses of Political Correctness are avoided, can research credibly be done in a given community by people with appreciably different basic concepts - or with a level of education, income and security differing sharply from the majority of the community where CBR is under study?

One early formal CBR evaluation, by expatriate agricultural economists (Berman & Sisler, 1984), suggests to me that technical competence can offset some of the perceived lack of credibility. The question requires close scrutiny as one hears a CBR Evaluation Bandwagon tuning up and bursting into song these days - some members serenading CBR, others singing all the way to the bank. Who evaluates the evaluators? Who decides which are the values to be evaluated? The bandwagon has some of the appearance of an elite trying to maintain control over a social phenomenon that threatens to get dangerously out of hand - one danger being that the 'results' of CBR may be reported as something other than what the controllers wish to see. (As CBR schemes lay great emphasis on the voluntary goodwill of communities, and the voluntary participation of trainers, teachers etc, will CBR evaluation also be done on a voluntary, no-fee, basis?)

Does anybody in the CBR game care two annas whether CBR is falsifiable? Is the concept not merely another attempt by a Dead White European Male to denigrate the hopes and ideals of disabled people? Few people involved with CBR are interested in research. Yet in a competitive world where every group needs to make its case for a slice of the global pie, and the pie-cutters suffer both compassion-fatigue and strong baloney-resistance, some evaluations need to be done with the sceptical mind, which never imagines a fine idea without also thinking of some ways to test its validity. In the CBR game, so far, there are few scientific mentalities.

We could all perhaps learn from one of them, Dr M.J. Thorburn, whose early work as a pathologist in Jamaica caused her to wonder why so many babies died of easily preventable diseases, and who looked for some answers. The answers she found suggested a new range of questions about practical measures to prevent diseases and disabilities. The practical measures led to further questions about how to transfer the knowledge and skills to far more families; and which methods of transfer worked best, for which parts of the population; and in what circumstances this was so, and why; and what evidence there was for the effectiveness of any of the measures; and so on, testing hypotheses and reporting the results critically, until finally one sees the rare combination of thirty years of published scientific work based in social action. (For recent references, see *ActionAid Disability News* (1993) 4 (2) 33. Earlier ones appear in Thorburn & Marfo, 1990, pp.27, 53-54, 72, 99, etc, and in standard medical indexes).

Whether CBR 'works' in Jamaica depends on definition; but Thorburn and colleagues provide evidence that will stand scrutiny, for the effectiveness of a range of social and family activities done by Jamaicans with their disabled children. Tough scrutiny is clearly needed to explain the growing number of positive project reports by external evaluators such as Finnstam et al (1988) in the Punjab, and Lagerkvist (1992) in Zimbabwe, which are then denounced by grassroots participants (e.g. Jaffer, 1990; Finkenflügel & Wolffers, 1993). Credibility is in question when a 'technical evaluation' of so-called 'CBR' activity, commissioned by a UN agency from people who never did such work (Shahabuddin, Khan & Begum, 1990), elicits an item by item refutation from a person

who has done so (Rehman, 1991). There is a need to ask why, when an 'internal' evaluator has conducted and reported methodologically careful studies of the program he is directing (e.g. O'Toole, 1988), aid agencies feel it necessary to commission an 'objective' evaluation (J.Miles & Pierre, 1994) which opens with the first author's declaration that he has seen something like a miracle, and continues in a journalistic vein. Who needs such evaluations?

HISTORICAL STUDIES & INFORMATION DEVELOPMENT

The previous section underlines the point that information is seldom neutral, if it goes beyond the railway timetable. In fact, the transmission even of easily documentable knowledge, e.g. the history of recent formal CBR approaches, is far from neutral and is worth examining.

Recent CBR History A mistaken impression has arisen, that "CBR is an innovative approach introduced by WHO in 1976" (Community Based, 1982, p.1); that before 1976 the view "held by all experts" was that "rehabilitation could be provided only in institutions"; and "not until recently did a handful of industrial countries start experimenting with integrated approaches" (Helander, 1993, pp.4, 94). The facts are different. Ten years ago, from meagre resources in Peshawar, I was able to cite examples of rehabilitation development work with people having all the main categories of disability, based in homes and communities around the world in the 1960s and early 1970s, e.g. by Boucebci, Cusson, Ghosh, Gudalefsky, Fichtner, Hindley-Smith, Huckstep, Ingham, Jaccard Freres, Levitt, Patil, and the Portage Project (Miles, 1985b, p.8-9).

It is easy to lengthen the list. At a conference in 1963, a mobile artificial limb supply scheme was described, which roamed across francophone Africa throughout the 1950s (Abadie, 1963). At the same meeting, the orthopedic specialist Huckstep noted that "Rehabilitation Centres are expensive, and need subsidisation. They are obviously not a permanent answer, although they fill a very definite need for a few patients." Levitt, at the same time, agreed that institutions could not be transported from Western countries to Africa, and asked for more efforts to discover "what is uniquely African and what does it mean to work in developing Africa?" In her own work, it meant that African parents of cerebral palsied children were "..shown how to handle their children at home as well as our treating the children at the clinic."

Earlier an Expert Committee (1958, pp.47-48) noted that the blind man had his place in rural Africa: "To take him away from his village and family in order to teach him skills which he does not need and probably will have no occasion to practise is wasteful, officious and even cruel. Probably he can be best helped by the type of scheme which is now being tried in Uganda, where local centres are beginning to train the rural blind for work on the land so that they can become self-supporting on small holdings."

Innovative vocational rehabilitation of blind people in the community in the early 1970s was done by CBM workers in India and elsewhere (Without holding, 1980). An even more basic plan for village schooling of blind children was visited in 1957 by John Wilson, in a remote part of rural Rhodesia. Thirty two blind children attended the school, built by the villagers, and followed an innovative, practical curriculum. "When they have finished this schooling, they will not be scholars, though some reach standard five in the

general curriculum, but they will know every inch and every activity of their village. They will be part of their community because they have never left it."

Such ideas were known in South Asia, where at least some social workers understood the social circumstances of handicapped people, and the resources available for rehabilitation. Banerjee in 1955 advocated a teacher-supported Home Training scheme (similar to the later Portage Project), that emphasized the potential of grandparents. Marfatia (1961, p.378) reported that "At the Indian Conference of Social Work [Bangalore, 1956] it was suggested that we should have for villages mobile vans carrying trained persons, who would educate parents in the training of mental defectives and make them aware of the types of services available in the cities for the training and rehabilitation of mental defectives. The suggestion encouraged others to ask, 'where is the trained personnel?..' A social worker pointed out that it would be much better if the mental defective was allowed to be adequately rehabilitated in the village setting only. ... In the village a mental defective is considered as part and parcel not only of the family but also of the whole community. He has a sense of belonging, resulting from his being accepted by the community for what he is."

Even in Pakistan, where service development was slower, experts noted in 1972 that services would "inevitably have to move out into the community as often and as much as possible" (Sohail, 1973). Pakistan's first conference of rehabilitation experts (Proceedings, 1975) considered many approaches, taking into account the economic resources of the country, the importance of the traditional network of mutual support in families, and the idea that handicap is socially constructed, so needs social solutions. Later, Anis-ur-Rehman (1990) warned against over-hasty closure of institutions, since the "breaking up of extended family system and lack of a coordinated community care program" was likely to leave mentally ill patients with no care resources at all.

Some 'experts' in some countries were indeed wedded to institutional practice, but by no means all were. Those who worked in institutions did not necessarily 'believe in' institutions, but found it useful to have a roof over their workplace, and an address where clients could locate them. Like Patil (1976), who studied rural rehabilitation methods around Jalgaon in the 1960s, they might start by noticing poor villagers "lost in big city hospitals", and be inspired to find ways of making rehabilitation aids from local materials. Fifty years earlier, Harnett (1927) at Calcutta discussed the adaptation of walking caliper splints to the Indian villager who seldom wore boots. The method was not very successful; but it was only at an outward-looking medical college that the various attempts at adaptation could both be studied and *recorded for posterity*.

In many developing countries, very few nationals were rehabilitation professionals, and those who were had trained abroad, there being no national training base. An early need was to establish training bases and develop experience (Expert Committee, 1958, p.46), experimenting with auxiliaries and para-professionals (Eedle, 1972, p.170). Such

bases were assisted, in South Asia and elsewhere, by American PL-480 funds (Groce, 1992, pp.56-61). With hindsight they may appear over-medicalised and western; yet without them there would have been far fewer referral and training centres to support outreach and community-oriented work in subsequent decades. Wilson saw in 1957 that every country needed a centre of excellence "to act as a focus of interest a demonstration of local possibilities and as a training centre." After that, however, he wished to "remove all the brakes and use every known method and improvisation which is consistent with the resources and life of the local community."

Clearly the WHO did take up CBR in 1976, following reports from its regional rehabilitation advisors from 1974 and earlier, as described by Hindley-Smith (1981, p.21). But what is the point of wiping off decades of service development before 1976? The term 'Community Based Rehabilitation' was not invented by the WHO in 1976. It was used in the USA in 1973 (e.g. Dunn & Korn, 1973) and probably several years earlier. There is thus no question of WHO 'owning' the phrase or having any special right to dictate what it means. Community-based services for people with disabilities were in vogue in the early 1970s (cf. the bibliography Alternatives in the Community, 1976; and Mamula & Newman, 1973). Jackson (1995) points out that Tizard's work, on care of mentally handicapped people in the community, began in 1948 and was highly influential for the next 30 years.

A hundred years earlier, the blind pioneer William Moon began home rehabilitation for blind adults and integrated schooling for children in England and abroad. In 1877 he reported statistics on the number of miles (c.124,000) travelled annually by 51 home-teachers of blind people (the teachers mostly being blind themselves, and employed by his 26 societies), and the number of volumes (c.100,000) circulated from libraries for blind people. Moon strongly advocated teaching blind children in ordinary schools. His home-visiting teachers were made available to schools to teach such children - they also enlisted the help of sighted children in doing so. The same methods using Moon's script took place in India, China, Egypt, Syria, Australia and Turkey in the 1870s, as well as specific cities of UK (Moon, 1877, pp.165-7; 1890; Meldrum, 1891, pp.92-112).

The UK Royal Commission on the Blind, the Deaf and Dumb, reporting in 1889, compiled tomes of data on various systems of instruction, locations, social and vocational education, from contemporary experts. Many issues debated now were debated over a century ago. The arguments are reflected in the Commission's report and minority reports. The merits of the home environment were emphasized, where the parents took an interest in the education and welfare of the disabled child. Existing systems of home-visiting teachers and social workers were discussed, as well as several forms of integrated schooling, with their comparative costs and effectiveness, and the experience of teachers and administrators in several other countries.

The witnesses and Commissioners recognised that the poverty in some disabled children's families was such that they were severely neglected, and thus deprived of any right to education. Their situation was such that an occasional visit by an itinerant teacher or social worker would be useless. The 'experts' concluded that for such children, including many with multiple disabilities, residential care and education was better than letting them lie mute and neglected in a filthy hut. One might agree or disagree with their conclusion - but unquestionably they did consider many alternatives, including practically all those which some people now think were newly minted in the 1970s and 1980s. Cole (1989, pp.1-65) documents much of the debate.

Generation of Wipers Does it matter whether people now choose to wipe out or misrepresent what was done before their own efforts? In fact there are several problems:

1. People who wipe out history, or simplify it to black and white, learn nothing from it; and prevent others learning from it.
2. We are all ignorant of most of what happened in the past - but this is not a licence to assert that which we do not know. Those who do may be poor guides to the present and future.
3. Disabled people and disability professionals in South Asia have lost their earlier disability history, weakening their capacity to cope with aid agency enthusiasts peddling the latest western trend, or to formulate policies blending the old with the new. People have been led to think that no formal services were begun by Indians, between some remote golden antiquity, and about 1890; and that little of value took place before 1950, and what was done was mainly by missionaries in their enclaves. It is understandable that after Independence there was some reappraisal of earlier activities; but it is pointless to simply wipe them out.

Material published recently (Miles, 1994) intends to wipe them in again, and to give clues to the lost history. Some may interpret the material in ways that I disagree with - but that is no problem. Interpretation is free - but we cannot begin, if the records disappear. There is documentary evidence of blind Indians learning to read and teaching others to read, and learning handicraft skills with which they earned their living, both in formally constituted special schools and ordinary schools, from the 1850s onwards; as well as less formal evidence for some people, with all sorts of disabilities, learning skills and playing their part in family and neighbourhood from much earlier. It did not all start with missionaries, though some missionaries undoubtedly made very useful contributions. Some of the most solid formal work was done by partnerships of Indians and government officers.

Some work was started by Indians on their own initiative, in ways which they considered culturally most appropriate. As recorded by his son (Banerji 1949), Principal Banerji vigorously opposed his Committee accepting the Government's offer to take responsibility for the Calcutta Deaf School in 1906, because "the institution was an unique one in India, founded by native enterprise, and he wanted to give the lie to the

general statement prevalent in those days of British Rule that Indians, by themselves alone, were incapable of giving anything new and constructive to the country."

A respect for the history of service development could also facilitate transitional periods, since these might be predicted rather than falling upon people unawares. The CBR field has followed some of the evolutionary path of Primary Health Care; and also that of community schools, once hailed as the cutting edge of social change. The CBR spectrum, after its heady days of youthful vision and pioneer enthusiasm, is in a phase of institutionalisation, where ideology gives way to accountancy, and 'community participation' (or 'compliance') becomes a footnote to 'management'. That is the underlying meaning of the rise of CBR operational management literature, from Khatu, D'Souza & Tamang (1985) to the better known handbooks by Murthy & Gopalan (1992); Jönsson (1994); Vanneste (1995). These handbooks, with their burgeoning array of forms to be filled, move onward from the sort of 'management' manual edited by Pahwa (1990) which largely concerns medical management of disabilities. Not all, however, attain the level of realism displayed in some ILO publications (e.g. Guide for Community-Based, 1994).

At the same time, CBR is being *re-professionalised*, with increasing attention by WHO to training the 'mid-level' (cf. Education of Mid-level, 1992; Promoting the Development, 1993) and by UNESCO to upgrading skills of junior professionals (cf. 'Guides for Special Education', ostensibly "intended for teachers, parents, and community workers", but clearly demanding more education than most parents in developing countries have). Any CBR approach needs to balance the conflicting demands of community participation, professional standards, career hopes of poorly paid or volunteer workers, and the individual needs of disabled people and families. No CBR program is ever completely 'in balance' - the balance is always shifting (unless the program has died, and nobody yet noticed).

A WHO Rehabilitation Division booklet now talks of "..an ideal situation in which a full-time mid-level rehabilitation worker is trained to work at a first referral level hospital, where rehabilitation services are provided for both in and out-patients, and to supervise the rehabilitation activities at community level." (Education of Mid-level, 1992, p.3) This "ideal" is far removed from earlier institution-bashing rhetoric; possibly because of a massive lack of interest by governments in adopting CBR as it was earlier packaged (ibid, p.3; Helander, 1993, p.189). In fact, ten years earlier, the government of Laos was so strong-minded as to implement a "modification of the WHO CBRS methodology", starting with the development of "intermediate or mid-level personnel instead of the community level" (Periquet, 1984, p.39). It is encouraging that some flexibility existed then, and some evolution of ideas is visible now.

Most of the possible arrangements could have been predicted by studying the previous 15/20 years' development of PHC, in which the false antithesis of "hospitals versus

primary health care" wasted much time and energy (Hospitals & health, 1987, p.8). It was predictable from the development of earlier services in UK at a time when the poverty of the masses was similar to that of half South Asia now. Further, the recent rise of health informatics and its application to resource development (e.g. Informatics and health, 1989; The role of research, 1990; Sandiford et al, 1992), suggest that disability service development may also enter the information age within a few years... (Why wait...?)

Disability Information & Development One can see through disability history the development of concepts, the slow accumulation of knowledge, the transmission of skills, the innovation of designs, and the information channels by which this took place. This is useful to understand what is happening now and how things will move in the medium term. It is sad to see how slowly information moved, and how clearly development was limited by flawed motivations and personality clashes. Yet it is challenging. The means now exist to access and communicate unimaginable amounts of highly evolved information around the globe very rapidly.

Much of this capacity is used for such activities as popular music, commentaries on ball games, reports on disasters, pornography, and ideological propaganda, reflecting the mental poverty of humankind and its preference for *kitsch* rather than problem-solving, creativity and challenge. However, the earlier phase of single channel mass media is passing; or, where governments have tried to keep control, it is being by-passed by technology. Iran - a nation proud of its vast cultural history - postponed national exams in 1994, because in the USA - a country with rather briefer cultural attainments - teams of men were kicking balls around a stadium. Iran's education minister judged that the nation's youth might prefer to spend the night watching World Cup transmissions by satellite, rather than getting their sleep and passing their exams next day (*The Guardian*, 5th April 1994, p.8).

There is growing diversification, to cater for interest groups which may be a tiny minority in any one location, but which total millions on a global basis. Such minorities become powerful as users of information, once the information technology has broken the spatial barriers - which it now largely has. This is why the debate on *where* CBR takes place - community, home, neighbourhood, centre, locality, institution or whatever - is outdated. It may continue for some years, but with decreasing relevance. The new focus is not *place*, but *information*.

The new wealth is information. Democratisation of this wealth is transforming power relationships around the post-industrial and newly-industrialising world (Toffler, 1990). Yet half of South Asia does not have keys, i.e. literacy and time-keeping, even to the older forms of information wealth; while 90% do not know the language of most global information networks, English. Population figures and development trends suggest that this situation will change little within our lifetimes. Where will they be, in the

information race? If, as in the first WHO-CBR project in the Philippines, the ability to read and write English is required down the line as far as the Local Supervisor (Periquet, 1989), they will be hobbling around in leg-irons. Even without such ludicrous demands, there will be increasing divergence of access.

A continuing very large number (i.e. several hundred million, out of South Asia's 1.2 billion) will have minimal access to basic education or information choices, for the foreseeable future (admittedly, at the current pace of change, foreseeable only 15-20 years ahead). Information sources will be all around, but they will be unable to hook in. This is not inevitable - but likely, on the basis of past developments and what we know of human nature, i.e. of ourselves. Disabled people among these economically weaker several hundred millions already have a grossly deprived and unpleasant life, by the standards of the urban middle classes (Asian and western). This will continue, unless unexpected major new factors turn up.

Information technology could be a significant new factor. It will probably not be, because for one or two decades yet the people who decide how modern IT should be deployed will fail to connect such resources with the situation of hundred-millions in serious poverty, or the disabled people among them. We are mostly not information-minded. The youngsters who *are* information-minded seldom know anything about how communities work. The high-tech information world seems poles apart from the space inhabited by blind and crippled beggars outside conference hotels.

So where is the democratisation of information wealth? In the next 20 years it can be expected to benefit not the weakest stratum, but the next few hundred millions, those who have emerged from survival mode, plus the more solidly established middle classes. I do not *happily* toss several hundred million of the poorest South Asians out of the information lifeboat. But I live now in a poor area of a western city, where unemployed, semi-literate English youths drift around intimidating old people and smashing up cars. Their consumption of material resources is vastly greater than that of their Asian counterparts. The 'electronic city' buzzes around them. Yet their participation in it, and prospect of participating, seem minimal. If that is so for them, one cannot expect much greater gaps to be bridged in South Asia. The new wealth creates its own shadow of new poverty.

Information studies & systems Formal studies of the methods and impact of information in economic and social development have grown during the past 20 years (cf. bibliography in Menou, 1993, pp.163-181; Development Communication, 1990; Kempson, 1990; Development Communication Report since c.1973; Moemeka, 1994). Admittedly, there are big problems in distinguishing causality among the many factors involved, and in applying lessons from information-rich countries to those in the earlier stages of information development. Kempson notes that few information studies have been

done in rural third world communities; and highlights the gap between the existing formal information services and the rural person with urgent survival-information needs.

Morinis (1980), however, was impressed by the vigour of information flow around informal rural Indian networks in a specific health context. My own studies have tried to highlight both the informal means of disability information exchange, and ways in which these could formally be supported, supplemented and qualitatively upgraded (Miles, various 1983-1995). The traditional community used to be the main purveyor of information - whether by gossip and grapevine, or by socialisation and informal education. As traditional community gives place to *gesellschaft* the reception and communication of information is increasingly an individually chosen, independent process - which is why the gap rapidly widens between those with, and those without, the capacity to acquire information.

The need for better information and communication on disability was underlined in an international meeting on the topic two decades ago (Hammerman, 1972). Remarkably, for that period, the report not only catalogued the problems of developing nations (pp.25-33), but recognised positive communication resources and networks to be tapped (pp.34-38). Nevertheless, by the end of the 1970s, Acton in a prophetic global overview (1979) admitted that "All of the objectives I have cited require a much more adequate flow of appropriate kinds and levels of information. From the approaches needed to improve the orientation of international planners and ministers of health to the most simple instructions prepared to assist an illiterate mother in dealing with an impaired child, from general guidance for village health workers to suggestions for teachers who have exceptional pupils, and particularly for people with disabilities, very little of the printed and audio-visual material we have gained is appropriate or effective. Experience has been gained in achieving these kinds of communications in other fields, and must be combined with our own experience of the problems we are discussing so that we can produce, or stimulate and support the production of materials in the languages or imagery needed and at the levels of the target audience."

Much of this remains true in 1995. Acton also noted the hazard of social magnetism, whereby western development agents find counterparts largely among the educated, urban elites of the third world, who may be equally ignorant of (or may conceal) the harsh realities of rural disability, and so tend to reinforce westerners' illusions - an ongoing problem.

My own writing on these topics in the 1980s did little more than elaborate on Acton's themes, from the perspective of Peshawar rather than New York. The difference of perspective led to an increased awareness that effective 'information transfer', from supposedly well-informed sources, required those sources first to learn something of the existing information among the people to whom they hoped to make the transfer (cf. Miles, 1983, 1985a, 1992b); and also the perception that dealing in 'bits and pieces' of

information, however numerous and at however many levels, is not enough; the entire rehabilitation field needs reconceptualisation in information terms. One practical outworking of this is the beginning of systematic analysis of information flow in rehabilitation systems (Miles, 1990c); and in surveys of local, national and international networks, of the sort attempted for the ILSMH (Miles, 1993b).

Disability information systems From the rural corner of Asia where I spent the 1980s, I imagined that information systems study in other development fields must have progressed rapidly, while disability information systems would also be conceptually much advanced in the West, so it should all be waiting for us in our late-developing disability game. This expectation has been only partly met. Information systems study, and the introduction of computing in developing third world health and education services, has been mostly for management rather than for the social communication of therapeutic or attitude-change information. Much progress has been made from the early 1980s, reviewed e.g. in Wilson et al (1988) reporting the application of microcomputers in primary health care management, and by a WHO Group (Role of research, 1990). However, this involved the use and study of electronics in information systems, rather than studying social information systems and supporting them with electronic databases and information technology.

The two sorts of system can converge, but are basically different animals. Methods of using computers in management, to support management, to better inform management, to monitor and control many employees doing multi-faceted tasks with many forms of equipment and finance, can be transferred from western to developing countries, with a little 'tropicalisation', some training, and a lot of anxiety. It can be done, and has been done and measured and found effective - at least in contractual, semi-impersonal management systems of the sort introduced or inflicted by development agencies. (How well this sort of management suits South Asian communities is a different question). The design of information software specifically for third world disability service management, e.g. in OMAR (Jönsson, 1994) begins a decade later, though of course some disability project and program staff have been word-processing, desk-top publishing and accounting since the mid-1980s.

There is some confusion between several meanings of 'information system'. Apart from systems geared to management, disability equipment databases have developed which may be called information systems or services - proceedings of one major conference show on the cover "Information Services on Technical Aids for People with Disabilities", while the rest of the text refers to "Information Systems..." (Duncan, 1982). Management information and database services differ from the sort of information system in where information needs, sources, flow and access appear (Miles, 1990c). That system again differs from an information and advice service; and differs from mass media communication of disability information, which may be seen by participants as a form of information system.

Development of information databases on technology for disabled living is an early entry point. Basic computing lends itself to this sort of listing - also the fact that aids are 'technical' resonates with the idea of information being 'systematised'. Daunt (1987) however, keeping in mind the purpose of the whole exercise, warns against "initiatives of information specialists, isolated from policy and the delivery of services." The creation and perfecting of universal equipment lists (now on European Handynet in nine languages) is not an end in itself - though the amount of effort required to keep technical databases accurate and up-to-date is such that staff easily forget the overall purpose. A British study on disability information provision noted that "Getting the right balance between committing resources to updating information and dissemination of information to potential consumers was difficult for most organisations to achieve." (Information needs, 1988, para.3.18). Around the same time, one of the major obstacles to 'CBR' in England continued to the lack of awareness, by both disabled people, carers and professionals, of what services were available (Clarke, 1987)

The 'Information needs' study (ref. above) preceded a national initiative to enhance information provision in UK, based on autonomous regional information services with some national coordination. Compared with the quantity and quality of information available ten years earlier, the results of the first two years of this initiative were very positive. Yet both appetite and palate grew faster than the feeding, so that the discourse of contributors to a recent evaluation conference (Information enables, 1993) is not so much happier than it would have been in 1983. Though better informed, they were now much more aware of the flaws, inappropriateness and lack of choice in the information available. Apart from these British studies, Roth (1989) provides a useful checklist for planning information services. Pan & Duncan's review (1980), while now outdated in its U.S. context, remains pertinent to the development of information services in many parts of the world.

Use of mass media to communicate positive disability information is comparatively recent in South Asia - though disinformation has appeared casually and unintentionally for decades (cf. Jangira & Ahuja, 1990). The 'attitudes' study conducted in Peshawar in 1982 used media coverage in 1981 to focus on attitudes, images, and possibilities for change (Miles, 1983). The report recommended that a national workshop be held on this topic, and that a Pakistan Information & Resource Centre on Rehabilitation be founded. This took five years to be implemented. A National Library and Resource Centre was slowly assembled, but like its Indian counterpart it had meagre resources and was little known or used. In 1989 it became attached to the National Institute of Special Education, which increased its practical usefulness (Special Education, 1989, p.21). A national workshop was held in 1988, and a handbook issued (Kolucki et al, 1988), the first such effort to involve artists, media professionals and disability activists. Kolucki later produced more substantial reviews of media and disability experiences in Asia (1989; also Kolucki et al, 1994).

Momentum for better South Asian media use grew slowly through the 1980s, with the occasional focus of a national workshop (e.g. Childhood disability, 1984) in India, and UNICEF promotion in Nepal (Gill, 1990). Raina (1993) notes that by 1987 a Media Cell was created, with regional task forces, to enhance the role of mass media in creating awareness on disability in India. A practical problem is that to be effective across the great range of disability concerns requires more coordination than is common among government departments. Prasad (1994, pp.47-71) usefully lists a variety of information activities and media production projects at national institutes. Meanwhile individual organisations continue to experiment with new and old media - whether puppet theatre, dance drama, printed cartoon strip - to communicate disability messages, usually without much formal evaluation. Mathur (1992) and Ojha et al (1993) describe some successful efforts with a range of targets. On the international front, O'Toole & Maison-Halls (1993) describe a variety of ways of making and using materials so that those involved are encouraged to think and extend themselves, rather than being rendered passive by being hit with blocks of ready-made knowledge. The resultant video-based series is in use in Asian countries and may be expected to continue nudging viewers into action.

Information impact Formal studies of the effects of disability information in the media are equally rare. A meeting of Asian disability experts (Report of the Regional, 1987) believed that "Public information and awareness programmes had little impact among the rural populations, policy makers, employers, trade unionists and politicians" (p.31), and recommended "innovative media channels" to do better. This statement did not seem to rest on any formal research, yet is plausible because of the dowdy image of disability services, combining worthiness, dullness and a vast pool of demand by poor people.

Research on bionic implants to overcome the disabilities of thousands of westerners, currently commands several hundred million dollars: it is new, future-oriented, science-fiction-made-fact, a strong commercial proposition, and it is carefully marketed. Research on CBR, which could affect millions of Asians, gets a few thousand dollars: it sounds worthy but boring, it is poorly presented, there are no votes in it, and the minister is busy today.

Menou and colleagues internationally involved with a year-long study on measuring the impact of information on development (1993) produced a useful review, but suggest that the complexity of the subject has so far defeated the rather half-baked efforts to get it taped and measured. They note (p.112) that one of the most challenging problems concerns the move "...from the model of discrete messages, where information theory has been deadlocked, to an acceptable representation of a plurality of messages and uses, which is the common experience of individuals and groups..." Rather than awaiting the results, at some remote date, of longitudinal studies, Menou and colleagues think that retrospective work could be done on historical evidence of health-care improvement, which "..might indicate the impact of information on development, specifically in

relation to the control, reduction, or elimination of certain diseases in developing countries. (p.77)

It is also true of historical evidence on disability, though this is less documented, especially in third world countries. Studies of information transmission with regard to the prominent South Asian disabling conditions of goitre and cretinism, lathyrism and poliomyelitis, suggest that the final problem, yet to be solved, is usually a human one. Technical information problems initially mask the human information problem. When the long-sought technical 'solution' is found, it turns out to depend on social factors for actual delivery. It is wise to begin with docile targets under maximum control, such as laboratory mice or the schoolgirls of Akron whose goitres Marine & Kimball (1917) mass-prevented (almost a century after the discover of iodine treatment). To extend the solution to Himalayan tribes has proved hardly feasible after another 80 years, because of human factors (Miles, forthcoming). The aggravation of polio paralysis by injections was reported 80 years ago, and steadily repeated ever since (Kern, 1914, in Wyatt, 1981). Injection aggravation seems to be the major factor in polio paralysis in India now (Wyatt et al, 1992) and in Pakistan from 1985 to the present according to our polio records in Peshawar (cf. Wyatt, forthcoming). Yet the point of the information does not penetrate the injectors, because of human and financial factors.

KNOWLEDGE IMPORT, EXPORT & TRANSFER

Consider first the attempted import of an Eastern therapy e.g. yogic meditation, to the West. There is a widespread feeling that modern Western life involves excessive stress, and a slight belief, among the Western educated classes in the past 80 years or so, that yoga and meditation might be of some benefit. Eastern masters of yoga arrived in Western countries, and attracted a modest following. Yet yogic meditation has hardly impinged on Western mass culture, nor is it officially promoted as a form of therapy, despite some positive results and a growing perception of need. Reasons for this lack of success are unclear, but probably involve conceptual blockage - the world of yoga and meditation is perceived as essentially religious or spiritual, little influenced by scientific materialism. The modern Western public does not conceive of itself in those terms.

The spiritual dimension is not ignored by the western public, but the (somewhat materialistic) notion that, for example, one can affect one's spiritual state by learning to breathe up one nostril and down the other, lacks appeal - quite as much as the early Christian tradition (equally misunderstood) that one can become a better person by wearing uncomfortable clothes. Sixty years ago, Coster (1934) pointed out that western perceptions of yoga were largely mistaken, and tried to show some of the common strands of philosophy and practice in eastern and western thought, which could facilitate mutual enlightenment. It would be hard to claim much success for this worthy undertaking.

This example is intended to show that it is not only Asians who find themselves in the annoying position of being considered 'backward' when it comes to adopting the benefits offered by another civilisation. Whether justly or not, the British have long been considered backward by Indians when it comes to spiritual understanding; by Californians, over bathroom design and household technology; by the French, concerning food, sex and philosophy; by the Japanese when it comes to training and workforce management; and by West Indians at cricket. To revert to therapeutic methods, it is hard for the Chinese to believe that British practitioners can really understand how to use acupuncture, or for Hungarians to believe that Peto's conductive education has been properly grasped and practised by Britons - who may have had four years' training in Budapest but who still can't speak proper Hungarian...

Selling KG A considered history of the 'transfer of CBR' to South Asia would be premature, as we are hardly through the first phase of the process. Perspectives may be gained, however, from earlier, no less idealistic, marketing jobs. In the later 19th century, export of the Kindergarten, from "a summery open-air environment with pupil-teacher ratios of about fifteen to one" in rural Germany, to urban England with classes of sixty to seventy children following a strict curriculum code, was attempted with evangelical fervour and a striking absence of consideration for cultural and contextual differences (Marsden, 1990). This example is interesting, because certain concepts of the child, childhood and learning are basic to western special needs and/or inclusive education

exporting, currently in official overdrive with a heavy UNESCO package (Ainscow, 1993). Kindergartens were exported to many other countries, including Japan in the 1870s. To succeed in Japan, they were obliged "..to go through a process of becoming a Japanese institution, which meant subordinating the Froebelian curriculum to the principles of Japanese national identity." (Wollens, 1993)

Import of kindergartens to India began with mission boards in the 1880s, with mixed success (Lamson, 1899). They were then promoted by the Bengal government. "The new scheme came into effect in January 1901 and was intended to revolutionise Bengali school teaching by the introduction of a system under which 'children were trained but not taught'." (Shahidullah, 1984). The main snag was that the teachers had not been trained before the scheme was launched. After four years, 95% of them remained ignorant of what they were officially supposed to be teaching. Remarkably similar drawbacks appeared some 80 years later, when efforts to modernise primary schools in northern Pakistan were evaluated. Bude & Chowdhri (1989) found there had been insufficient training; teachers, unfamiliar with the material they were expected to teach, reverted to the traditional method of rote memorisation.

The efforts to train community health volunteers, in the Indian scheme noted above (Jobert, 1985), are similarly instructive. Their training "..was the most crucial moment in the implementation of the programme. This was where the much touted transfer of knowledge from professional institutions to community representatives was to take place." What actually happened, in the usual rush to get the scheme rolling, was a seriously flawed 'training of trainers', with minimal interest by state governments, followed by sharp compression of great masses of knowledge which was dumped onto the community volunteers, out of context and with a complete absence of the social dimension of health. What the volunteers gained was a fair knowledge of the use of some drugs.

CBR Training The key role of multi-level training in development of CBR, and the current dearth of trained and skills personnel, are repeated in reviews from many countries. Yadav (1994) sees it as a major weakness of CBR in India, that "National Institutes are fully aware that trained manpower for CBR are very few including doctors. In spite of this, no effort has been made by these institutes to work in this direction. Their training programmes are only institutional based. They train people to cluster round the urban areas or to migrate to other countries." (This sounds plausible, from experience mentioned above and from the nature of the training needed. It is only fair to record that National Institute representatives have disagreed with Yadav's remark).

South Asian societies remain highly stratified, and educational certificates play their part in determining the individual's status in the pecking order. Further, the age-old tradition is that if someone has knowledge and skills which you wish to acquire, you go to him (occasionally her), bearing gifts. He does not come running to look for you. On the contrary, he may initially ignore you, or set some difficult task, to find out whether

you seriously wish to learn. Against this background, we have the introduction of CBR some 15 years back in Kerala and Pakistan's Punjab, with medical colleges as resource bases, and slow efforts to develop it elsewhere in South Asia. Program Organisers and Local Supervisors needed to be trained across a variety of medical, vocational, social and educational issues, by people who had not themselves engaged in what the organisers or local supervisors were preparing to do but had spent, and expected to continue, their working lives mostly in institutions.

The whole thrust of the scheme ran counter to the highly stratified indigenous system of knowledge and certification, in that it proposed to train people to *give away* information and thus mobilise people to do for themselves what would normally be expected to be done for them by someone trained and certificated to do so. In the process of giving away information, the LS was to visit people in their homes, rather than the people going to the LS as to a teacher. The 'deposit' of information was to be in the form of a printed book, or sections of it, written by foreigners, translated by urban professionals.

It is hardly surprising, then, that Jaffer & Jaffer (1990) reported from the Punjab that "the LS and rehabilitation staff were perceived in the traditional role of a government servant (e.g. electricity meter reader), salesman, beggar etc. ... the rehabilitation team often perceived themselves as door-to-door salesmen of a multi-national organisation trying to sell a new product, using free medicines as bait." An evaluator pointed out that, with the very low female literacy rate in the area, the reliance on a printed manual made little sense. It probably made far more sense in Kerala, at the other end of the literacy scale; but that State is well known for its atypical features. Kerala was a good place to start, on the principle of 'doing the easier thing first'; but not necessarily a good model from which to scale up to nationwide coverage.

Varma asserts in 1994 that "WHO C.B.R. model was implemented in Trivandrum (Kerala) but could not be replicated in other parts of the country. It is still confined to Kerala." This does not take into account the many smaller projects run by NGOs (cf. Pandey & Advani, 1995, pp.131-137), but it suggests that there are serious problems in effecting the 'transfer of knowledge', and even more so in achieving the needed transformation of attitude and restructuring of resource allocation.

Zinkin & Morley (1993) note that most of the students on their training course for CBR teachers and planners had themselves "experienced a hierarchical, teacher oriented education system"; and one of their justifications for siting a CBR course in London was that it enabled students to escape the constrictions of professional bodies in their home countries. A document used as a handout for visitors to that CBR diploma course talked of professionals "..who fear a dilution of the quality of rehabilitation care or see a threat to their own social and economic position. In many countries rehabilitation and special education have a short history. There is little public awareness of what, for example, a

speech therapist, orthopaedic surgeon or special teacher does. When the apex of the skills pyramid scarcely achieves recognition, the time is hardly auspicious to insert an extended base of briefly trained workers." (Miles, 1987b)

Yet after the CBR National Policy has been agreed at the most senior level (if this ever does happen in any country), and the plans have been drawn up, and ministers have posed for photographs with some disabled kids at the launch ceremony, and the Finance Secretary has quietly slashed the budget, and a few semi-literate nephews have been given senior positions on large salaries, and so forth, when it comes down to the training of the trainers, who will transfer knowledge to local supervisors, who will run from door to door selling the idea to family members, who are then supposed to do something positive with the disabled person - the initial training responsibility is back with the same institutional professionals who are unlikely to find any strong personal motivation to make a good job of it; who have little background with which to do so, even if willing; and who have very little reason to find the whole scheme remotely credible.

This is not to say that it cannot be done. It may be possible for training schemes to succeed, at the three or four successive levels required. There seems to be more chance of success if planners would stand back a little and ask themselves:

- What are the information contents required by the scheme at various levels - i.e. all the concepts, knowledge, skills, design and feedback mechanisms?
- Where and with whom can such information be found?
- What means already exist for its exchange and transfer, whether formally or informally?
- What motivations exist for anyone to engage in, or to oppose, such exchange and transfer?
- What experience is there of earlier comparable training schemes; are there any evaluations of their performance; and can anything be learnt from them?
- Are there any cultural practices that could clearly help or hinder the training processes and subsequent application of knowledge and skills;

The questions are so basic as to be almost insulting - if it were not that so little heed seems to be given them.

The introduction of CBR training schemes, as earlier with PHC schemes, involves struggles between medical, social work and educational interests for control of the syllabus, with some internal battles between those whose interest is mainly in disabled children and their parents, and those whose experience has been with disabled adults.

Asian countries where such problems may have been bypassed, such as China and Vietnam, had previously engaged in large-scale social engineering and have the apparatus for mass indoctrination already installed. No doubt they also have some problems of corruption and inertia, but it must be comparatively harder for people with knowledge and skills openly to oppose a scheme for the wider dissemination of what they have. Whatever

the drawbacks of totalitarian states, in terms of western-practised human rights (e.g. the right to dine in comfort and security while children starve on the television), they are more likely to provide the basic requirements for national-level CBR, such as a strong political will to make available basic services at grassroots, and an existing PHC network.

The next 20 years may see some convergence of views, as these countries try to modernise their economies without becoming hard-faced capitalists. Hai (1993, and personal communication) suggests that CBR has been adopted very rapidly in Vietnam, aided by the previous establishment of a Red-Cross trained member in every family. There was no need for marketing by door-to-door salesmen; nor for what Momm (1994), discussing disability development in Central and Eastern Europe, called the "frantic rush of Western experts and advisers into the former planned economy countries, who, often with missionary zeal, hoped to sell what they knew as the best system - which usually was their own..."

CONTROL OF INFORMATION

By no means everyone sees merit in the wide dissemination of disability information, or in efforts toward accuracy and providing evidence for what is asserted.

Governments tend to censor all sorts of information and control its flow, as the appetite for interfering in people's lives grows stronger with exercise. Modern information technology makes it harder for governments to indulge this propensity on the mass scale, but easier to monitor individuals and small groups. One might not think that information about disability and rehabilitation would be perceived as threatening to the state - but if Froebel's kindergartens could be banned by Prussian officials in 1851 as arms of revolutionary socialism, there can be few limits to the potential paranoia of some temporal masters. Sometimes governments are persuaded by professional organisations to ban anyone without a particular qualification, from working with disabled people. We may yet see a disabled person jailed or fined for attempting to assist herself while being found unqualified to do so! The usual argument is that quacks are making big money by duping unsuspecting families with a disabled member. (The right to make big money should be reserved for qualified people...?)

Rehab Professionals may have a financial interest in controlling information. It is interesting to note the eclipse of Moon's embossed script, by various sorts of Braille. Moon's script was introduced in the 1850s and made the running until the 1890s, with adaptation to a dozen Indian scripts, until it was overtaken by Braille script. Braille had the advantage of taking less space, and being cheaper to produce. Moon had the benefit that it could be learnt quickly by adults - within days - because its shapes followed letter shapes rather than being a code of dots. Braille required experienced teachers, who were scarce and so in greater demand. Braille was hard for older people, especially if their hands were work-hardened or desensitised by a medical condition. Moon could be learnt by almost any interested person, and then taught to others - William Moon taught it to sighted children, who were delighted to go out and teach blind children and adults. As blind education became professionalised, Moon gradually waned (though it has revived in Britain during the past 30 years, for other reasons). Moon did not require professionals.

Information professionals can be prominent controllers of information (Menou, p.28), whether because they are employed to do so; or through the belief that "people are not used to making a choice between two or more options because daily life has few or none to offer" (Helander, 1993, 98-101), so the decision should be made for them, by experts; or for other reasons, some of them legitimate. All teachers and trainers control the information they impart - students expect them to do so. Yet when the 'students' are millions of people in every country and culture of the world, it is harder to argue (as some do) for restricting the information they should be given, to just one or two manuals. There is at least 1,000 years' experience of publishing health information for the general public, since Al-Razi (who died in 925 CE) produced *Man la Yahduruhu al-Tabib* ('He

Who Has No Physician to Attend Him') (Karmi, 1985). Do we condemn David Werner for writing *Where There Is No Doctor*, merely because it had been done before?

In a situation where disability information resources are scarce, such as northern Pakistan, it seemed wiser to us to prioritise the training of staff who would continue to accumulate useful experience with many disabled or mentally retarded children and would become resource banks for many people - rather than to prioritise the spread of detailed information directly to families for home use, where it would not accumulate with any breadth of experience and was unlikely to be accessible more widely. (In fact, we also did a lot of individual family counselling - not because it was a strategic use of resources, but because it was hard to refuse people who arrived seeking something that we had and could give). This is, I believe, a legitimate and even necessary form of information control by prioritisation - even though it ran counter to many professionals' one-to-one orientation.

Urban experts, as already mentioned, are interested in the potentially lucrative 'evaluation' business, and may impose their ideas of what constitutes worthwhile, cost-effective benefits in the lives of rural or slum-dwelling disabled people and their friends (who are supposed to be giving their efforts voluntarily). The benefits to the evaluators themselves, for their few weeks' expert work, may be rather more tangible. It would be interesting to compare such benefits with the inputs actually reaching disabled people in CBR schemes... but such information is unlikely to become known - it would not be considered to be 'in the public interest'.

Foreign experts can act to stifle any criticism from 'difficult natives', as Jaffer & Jaffer (1990) recorded. Sometimes the censorship is as crude as the pasting-over of one opinion with another, as in publication ED-86-5, UNESCO, Nairobi on assessment of handicapped children. The African who wrote the introduction dared merely to suggest that a couple of issues raised by the foreign expert "need to be further discussed by professionals in Africa" (p.3). This rebellious idea was discovered at a late stage in producing the document, so could not easily be cut out. Instead, a further page was pasted over the top, with the offending paragraph missing. Print on the original page is visible below, so with the aid of a knife once can split the pages and reveal the guilty comment. A later edition eradicated it...

Organisations of Disabled People may wish to control information - e.g. by asserting that only information derived from a genuine Disabled Person is valid - nobody else can *really* understand. This is understandable as a reaction to the marginal, low-power situation in which many disabled people live - but it is still information control, based on self-interest and extending to interference with other people's information access. Western disabled people can be as patronising as non-disabled westerners to easterners. No doubt DPI's Henry Enns (1991) meant well when he said that disabled people in the Middle East "have only started to organize themselves recently" - but how much more

encouraging if DPI began by recognising the Middle Eastern disabled people's organisation of 331 BC, formed by several thousand mutilated Greek soldiers in Persia (Diodorus of Sicily, XVII.69; Quintus Curtius, V.v.5-24) over 2,300 years before DPI was born. It is not disputed that some modern Middle Eastern groups are of recent origin - but they inherit an old and rich tradition, if the information is not kept from them.

Aid & Development Organisations are active in the control of disability information, e.g. as reviewed above in the 'reconstruction' of recent CBR history. However, UN agencies are in a difficult situation, in that they have no more than a persuasive or propaganda role - they can seldom do anything themselves and learn by doing it, but depend on governments to pick up their suggestions, sometimes with fatal twists added. They are obliged to scratch around for their own budgets, from governments which do not necessarily stand to benefit from them. According to convention, they must constantly deal in diplomatic half-truths with government officials whom they may see as corrupt idlers living on the backs of the poor - and who may see them as overpaid, hyperactive nuisances. It is not surprising that, in the process of dressing up a scheme for disabled people in appealing language, they may sometimes fall into the error of believing their own propaganda.

External evaluation is needed of the performance not only of implementing agencies but of the foreign aid agencies with respect to CBR. Do they learn anything from their expensive mistakes, or do they simply conceal them? Is there any ongoing institutional memory to save them from repeating blunders? What do aid agencies actually do with research reports and other sorts of information? (It is worth asking this, before embarking on research...)

IN CONCLUSION

This paper, within the constraints of space and the limits of information available, could merely sketch a few of the issues concerning research and disability information exchange. The bibliography may provide clues for verification of what has been suggested, and for ongoing studies.

The complaint may be made, that the western works cited here are not readily available in most of South Asia, and the eastern works are not available in most western libraries. However, there is potential for these spatial problems to be overcome in the following years. It is important that people should be motivated to do so. If interested people gain access to libraries, but do not know what to look for, they will not be much better off. We cannot expect generalist librarians to understand our information needs, unless they are provided with some bibliographical starters. We cannot expect intelligent students to do research on disability information, without some reassurance that material actually exists that is worth looking for and working on. We cannot expect aid-giving organisations to fund such studies, or to assist in making material more widely available, if there does not seem to be any solid body of work that is worth circulating.

The limitations of all our information must also be recognised. To compile and annotate a Directory of Bibliographies listing Overviews of Research on Information concerning the Situation of Rural Mothers with Disabled Children would be long and arduous - yet, at five removes from actual mothers, it is less arduous than trying to supply and apply information directly to them. Young women, who physically make the human future, are under maximum control in most societies. The efforts of proselytising westerners, or easterners, to capture their minds for EPI, growth charts, Portage etc are frustrated by powerful counterforces. Look out for her, the village mother, whom everyone controls yet who is beyond our reach:-

There she stands,
the village mum,
In humble dress
And humble mind,
There's none counts less
than her, in humankind.

She's seventeen
and cannot read;
She learns the lore
Of village mums
From Mum-in-law,
Beneath whose thumb
She labours long
these three years gone.

She's far beyond
the reach of men,
Of Western men who
Know What's Best,
Who come with plans
To straighten out
The backward world,
The Third or Fourth
or Southern World.

She does not know
their plans for her,
Hygienic plans,
Nutritious plans,
With graphs and charts
And BHUs, and ORS
And EPI and PHC and
all the latest quackery.

Yet clever though
these plans are laid,
And large the sum
Of foreign aid,
They cannot reach
The village babe
without the village mum.

There she stands,
the village mum,
With one at breast
And one on hip
And one in tum,
Inviolate.

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